

LTCANI

Response to Proposals
for Health & Social Care
Reform in Northern
Ireland

May 2008

Introduction and summary:

The Long Term Conditions Alliance Northern Ireland (LTCANI) welcomes the opportunity to respond to the document 'Proposals for Health & Social Care Reform'. As an umbrella group representing approximately 500,000 people with long term conditions in Northern Ireland we broadly welcome the proposals, and in particular the commitment to a patient centred service. We believe that the duty to engage set out in the earlier legislation is a vital step forward and we trust that there will be no dilution of that principle.

As organizations which work closely with patients and users we are strongly committed to real and effective user involvement, known as personal and public involvement (referred to throughout the document as PPI). We believe PPI is vital both for targeting resources and for involving patients in taking responsibility for their own conditions and care. We believe that the proposed Patient Client Council will have a key role in promoting engagement and we strongly believe that the PCC should be province wide, as in Option I in that section.

LTCANI Background:

The LTCANI was established in 2005. The Alliance is an umbrella body for voluntary and not-for-profit organisations working with people with long term conditions in Northern Ireland. Collectively, LTCANI members, who include **Action Mental Health, Alzheimer's Society, Arthritis Care, Asthma UK, Chartered Society of Physiotherapists, Diabetes UK Northern Ireland, Epilepsy Action, NI Chest Heart and Stroke, the MS Society, Macmillan Cancer Support** and the **Northern Ireland Cancer Network**, represent approximately **500,000** people with long term conditions in Northern Ireland.

A long term condition is a condition of prolonged duration that may affect any aspect of a person's life, the impact of which can be lessened by effective self management. Effective self management includes – awareness /information about their condition, structured, condition specific, education, emotional and

psychological support and access to the right treatment and health and social care professionals at the right time.

The LTCANI's objective is to ensure that people living with long term conditions in Northern Ireland receive the medical care they need and are supported in such a way that they are able to have control over their condition and can fulfill their potential.

As individual organisations, members of the LTCANI provide services to people living with long term conditions. In terms of putting in context the impact of living with long term conditions in Northern Ireland:

Prevalence

- *There are 230,000 people with arthritis in Northern Ireland*
- *There are over 58,000 people diagnosed with diabetes and an estimated 20,000+ undiagnosed*
- *At least one in five people in Northern Ireland will experience problems that affect their mental health and suicide is on the increase with around 150 recorded deaths each year*
- *Approximately 17,000 people in Northern Ireland have dementia*
- *There are approximately 150,000+ people with Asthma, of this total 35,000 are children*
- *There were 5,002 deaths in Northern Ireland in 2005 attributed to all types of circulatory diseases*
- *Mortality rates from coronary heart disease (CHD) in Northern Ireland are among the highest in Europe. 2,708 deaths in 2005 were due to CHD*
- *1,451 people in Northern Ireland are disabled on a long term basis by stroke in 2005*
- *Over 80,000 people are suffering from the consequences of COPD , not just for months or years but often for decades*
- *There are in the region of 13,000 people with epilepsy in Northern Ireland*

- *Between 3,500 -4,000 people have MS in Northern Ireland*
- *Cancer accounts for approximately 8,000 new cases per year in Northern Ireland*
- *There are currently approximately 40,000 people living with a diagnosis of cancer in Northern Ireland*

Economic

Long term conditions account for:

- *52% of all GP appointments*
- *65% of all outpatient appointments*
- *72% of all in-patient bed days*
- *Almost £7 in every £10 of NHS funding is spent on the treatment and care of people with long term conditions*

The LTCANI priorities include:

- **A strategy for long term conditions in Northern Ireland**
 - **A commitment to taking forward genuine PPI within the Northern Ireland Health & Social Care system**
 - **Support for self management training and other forms of structured, condition specific, patient education.**
 - **Prevention and early diagnosis**
 - **Exemption from prescription charges for all patients with long term conditions**
 - **Integration and smooth transitions between services**
 - **Support for ending inequalities in health**
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General Comments:

The LTCANI welcomes and supports the Minister's commitment to achieving a modern and responsive health and social services. In reference to the five guiding principles as outlined within the Executive Summary the LTCANI would make the following comments:

1. The LTCANI supports the principle of a service that is centered on the needs of patients, clients and carers. It is essential that the proposed structures create an environment which will help deliver strategies, policies and objectives as envisaged by both the DHSSPS and the LTCANI.

As an umbrella organisation representing approximately 500,000+ long term service users, the LTCANI believes that the new proposals must enshrine public and personal involvement (PPI) and that people living with long term conditions have a key role to play both within their own personal care as well as being publicly involved in the design, planning and monitoring of their respective services.

As outlined in the document and many other DHSSPS policy documents, the NHS structures need to change dramatically to meet the major health challenges facing our society. As the emphasis moves towards health and well-being, through prevention, early identification and good self management, then the proposed structures must reflect the policy objectives. The LTCANI believes that the new structures must properly embrace PPI. Not only would this place service users and carers at the centre of the Service, it would help support the other four principles outlined within this document.

We would also outline that running parallel to PPI there is a need to focus on the importance of informed choice and citizenship. The LTCANI believes that informed choice and citizenship are important in promoting health and well-being. If a service user is informed this will enable them to make the best choice regarding their health. Equally, if

the 'culture' of service users is centered on citizenship, then they will feel they have a key role in staying healthy. Additionally, if diagnosed with a condition, they will feel they have a key role in managing their health as well as bringing personal experience and expertise. Health is not just about taking the tablets.

2. The LTCANI supports the principle of a service that is efficient. We understand the importance of achieving value for money and also of reducing unnecessary waste and eliminating duplication. As long term service users, people with long term conditions will need to be provided with the appropriate 'tools' to properly manage their conditions. The tools are information, emotional and psychological support, structured education and access to both the appropriate treatment and health and social care professional.

We would stress that in striving to reach this principle, the longer term effects of decisions need to be given greater weight. For example, evidence has shown that investment in condition specific education can help delay or even prevent serious complications in the longer term, can reduce the demands on GP's, and help to keep people at work and independent.

3. The LTCANI supports the principle of health and social care organisations being forward looking and innovative. The proposed new structures must be constructed with the view to delivering on the DHSSPS's long term vision of health and well-being. The LTCANI believes that the structures must include key multidisciplinary / multi-agency teams which are expert in redesigning health system in order to meet the growing needs of people with long term conditions.
4. The LTCANI fully supports the principle that individuals who use services must be given the opportunity to voice their concerns and be sure that they are being listened to. As outlined within the DHSSPS's guidance on PPI, we believe that the core principles of dignity, respect,

equality and fairness for service users need to be enshrined at every level in the new structures.

People with long term conditions need to feel engaged with their own care and to feel responsible for their own health. They know a lot about their conditions. They have a real contribution to make, both in their own personal care and in shaping the services which support them. Their input can help the health and social service to target its scarce resources more effectively.

Effective user involvement goes well beyond the level of changes envisaged in the RPA proposals. It requires a culture change, and genuine engagement at a variety of levels. It does not mean a few places on committees, though there should be specifically patient/user representatives on the key bodies. It does mean involving users and user representatives in the design and monitoring of the services which affect them, and is about improving services, increasing efficiency and meeting people's needs.

We welcome the commitment to local engagement but would stress there is also a major need to engage with people with specific conditions and health issues. People with long term conditions will relate to and have expertise on their own condition. The incidence of such conditions will not vary much across Northern Ireland, though access to, and quality of, services may vary. When designing, developing, commissioning or monitoring services it is essential to engage with those most affected.

For example, it is important when looking at improving services for people affected by cancer, that commissioners and providers are working in partnership with relevant 'communities of concern', namely people affected by cancer in this case. As well as localities it is vital to engage with constituencies of interest, communities of concern.

5. The LTCANI support the principle of continually striving for quality and standards. We would emphasize the importance of informing people. In this modern age, there are many expectations on what a health and social service should deliver. The LTCANI believes it is fundamental that service users should be informed about what care they should expect and that the care should be off a high standard. Additionally, we would outline that informed service users need to know what quality care is in order to identify if they are receiving quality care locally from the health and social service provider.

We welcome the development of service frameworks which set out the standards of care which individuals can expect to receive in specific areas of care, such as respiratory, cardiology and cancer to date. We welcome the openness and transparency which these will afford. We would however, caution that where such standards are set service users will anticipate the follow through of resources to meet the implementation of standards highlighted.

Comments on the proposed Regional Health & Social Care Board (RHSCB) and the Local Commissioning Groups (LCGs):

In reference to the constitution, the LTCANI agrees that the Board must reflect the cardinal principals of good governance. The LTCANI believes that PPI at the Board level needs to be enshrined within its constitution. We would suggest the creation of a PPI 'champion' at Regional level. With Departmental policy focusing on a patient centered approach and with commitment towards PPI, there is a need for a post at regional level which will have the responsibility for making sure that PPI is taken forward at all levels of the NHS in Northern Ireland.

This position will also have a key role in working closely with the Patient Client Council structure. Creating a post at this level will indicate the seriousness of

user views within the planning and performance of the NHS. User involvement and engagement needs to be driven at this regional level in order to maximize on the benefits proper PPI can bring.

We would point out that the focus on quality of care for service users, accountability, transparency, efficiency and effectiveness would be enhanced with the inclusion at regional level of an Executive Director for Children and Young People Services, as this is a significant area that has been under-represented in the past.

This position would help focus in on supporting children and young people to better manage their condition and help them achieve the highest quality of life and the most positive of outcomes. Additionally, the creation of this post would help meet the challenges concerning the transition from paediatrics to adult services.

In reference to function, the LTCANI would highlight that section 4.4.1 refers to strong performance management and improvement. The paper mentions that the RHSCB would be 'responsible for ensuring improvement in the care provided for those with long term conditions and for increasing standards and quality levels.' We believe that this function further strengthens the need for PPI to play a central role with the RHSCB and that accountability must be transparent.

To identify what care improvements need to take place, there needs to be closer partnership working with people with long term conditions and with the LTCANI. The LTCANI has a key role to play in helping to facilitate PPI, with the overall objective of monitoring standards and quality.

We would also like to comment on financial management outlined within section 4.4.2. The LTCANI stresses the importance of the financial regime and any alignment of resource allocation must focus on more than quantitative results. There must be a balance struck with quality performance.

Commenting on commissioning as outlined in section 4.4.3., the LTCANI welcomes the commissioning functions and strongly supports the concept of stronger link with local communities. We specifically welcome stronger links and working in partnership with voluntary and community sector organisations. Once again we emphasize the importance of engaging with condition specific communities in the monitoring and planning of services concerning commissioning. We believe further clarification about how the voluntary and community sectors fit into the new structures and the role the sector will play.

The LTCANI believes that further clarification is needed concerning the relationship between the RHSCB, its sub committees, the Local Commissioning Groups (LCGs) and a Patient Client Council(PCC) The current relationship pathways as described in the diagram gives cause for concern in relation to the input of stakeholders and patients and also to PCC relationships with LCGs.

We would also like more clarification on the phrase 'relevant bodies' identified under the commissioning functions section. There are potentially very significant issues here, such as practice based commissioning and/or the privatization of services in Northern Ireland. If such steps are contemplated they would need to be much more fully set out and discussed than is possible in the context of this process.

In terms of responding to the proposals concerning LCGs, the LTCANI would make the following comments regarding the constitution, functions and governance:

- The LTCANI have no particular comment to make regarding the geographical placement of the LCGs.
- In terms of the co-terminosity, we believe LCGs and Trusts should cover the same area as this strengthens PPI. For example, if LCGs, Trusts and the PCC model (as outlined in Option 1) covered the same

area it would enhance partnership working and help in the monitoring and comparison of services.

- The restructuring proposals would also help to take forward the proposals for the Managed Clinical Networks (MCNs) in specific conditions. For example the creation of MCNs in diabetes across the five areas would help to monitor, implement and evaluate diabetes services within a framework structure.
- In reference to democratically elected representatives taking up positions on each LCG, the LTCANI believes that this is the only way representation within a geographical area can be truly attained. Locally elected representatives have a mandate to represent a certain geographical area and local councilors have a key role to play as they have an awareness of local issues and can be an important line of communication between the community and the LCG. We welcome the opportunity to actively engage with local representatives in order to help prioritise issues of concern for people living with long term conditions.
- However, the LTCANI believes it is not realistic to expect local government councilors to be the 'expert' on all the health issues in their area. In order to properly support the representative role, we believe there needs to be some sort of direct user representation on the LCGs. We would stress that 'lay' representation, as presently understood, is not the best way of supporting PPI. No one person can effectively represent all service users and conditions, but it is important that there is 'user/patient' representation rather than merely 'lay'. There is a need to expand PPI at this level and to properly resource PPI at this level.
- As the LCG has a crucial role in supporting people with long term conditions, we would also stress the importance of making sure that there are safe guards put in place to make sure that the work of the LCGs is not 'politicized' at any level or by any specific grouping.
- In terms of composition, the LTCANI would suggest that the role and function of each representative needs to be clarified and specified.

- The LTCANI would also seek further clarification on identifying the relationship at LCG level with the PCC's local equivalent.
- In terms of the relationship with the RHSCB, we believe that the RHSCB representative should have a two way role within the LCG.
- In conclusion, the LTCANI welcomes the commitment within section 4.8 to greater engagement with the voluntary sector and look forward to meeting and working with the new structures.

Comments on the proposed changes to the Department of Health, Social Services & Public Safety (DHSSPS):

In reference to the functions, governance and staffing proposals for the DHSSPS, the LTCANI would make the following comments:

- It is the view of the LTCANI that the size of the DHSSPS should reflect its role and function and the principle of efficiency. We would stress that as long as the new DHSSPS ensures there are high standards on service delivery across Northern Ireland, irrespective of postcode. We believe that the DHSSPS has a fundamental duty to ensure that people living with long term conditions have timely access to quality services across Northern Ireland.
- We welcome the statement under section 5.2, bullet point 8 'the strategic prioritization of resources taking account of NICE recommendations and National Service Frameworks'. LTCANI would like to work in partnership with the DHSSPS to help implement the guidelines and standards of both NICE and the National Service Frameworks. As representative organisations of people with specific long term conditions, members of the LTCANI would welcome working closer both collectively on long term conditions as well as condition specific issues.
- Under section 5.2, bullet point 9, we would seek further clarification on the reference to 'strategic policy development including the development of community, voluntary and private sector capacity and service delivery'. This is a crucial area for future development and the

LTCANI would need both further information on what this means, timescale, resource commitment and strategic direction. If this is a key area for development then more information is needed in order to capacity build within the sector.

- In terms of function, we welcome the focus on longer term health and well-being outcomes as prevention and self management are important for people living with long term conditions. We believe we have an important role in helping to deliver this and look forward to working in partnership with the DHSSPS to develop and possibly help deliver this.
- LTCANI notes section 5.13 b. regarding the possible application of appropriate incentives and sanctions to the RHSCB to ensure there is a comprehensive performance improvement across the entire health and social services. We would seek clarification as to whether the views and needs of service users gathered as part of PPI will play a role in improving performance at this level.

Comments on the public health proposals:

The LTCANI welcomes the greater presence and emphasis placed by the proposals on public health and we would support the creation of a Regional Public Health Agency (RPHA).

Public health challenges such as the impact of an increasing ageing population combined with an increasingly overweight population will need a strong body / organisation. The role and remit of this organisation will be critical as there needs to be a drastic shift towards prevention and health improvements, and it is unlikely that that agenda can be effectively driven by organisations whose primary function will inevitably be the delivery of health and social services. This shift must not just be evident within society but also throughout the health and social service and it must be evident in all aspects of the delivery of services. We support the objective of reducing inequalities in health.

The LTCANI believes that PPI can play a key role in taking this objective forward. PPI, if taken forward properly, is crucial to helping the population both witness and adhere to the public health message of a healthier lifestyle. In order for this to happen, service users must be involved in the planning of the message. For example, if we are aiming to tackle obesity within children and young people it is important to engage with children and young people to identify what is the best way of getting this message across and also to get buy in from these stakeholder groups.

For this structure to properly function and meet the objectives as envisaged it will need to look at partnership working. The LTCANI considers that in its present form the proposals come across as being 'top-down' in nature and approach. As LTCANI members are actively engaged in raising awareness and focusing on prevention and self management within their respective conditions and at a local level, we believe there needs to be greater partnership working both with voluntary and local community organisations. We would also point out the need to clarify the health messages, in order to make sure that the public does not get conflicting messages on prevention and self management.

We would welcome further clarification on the composition and governance of this group. For example, will the RPHA have a Board, if so who will sit on this? Additionally, will the RPHA have a public participation strategy and what will its relationship be with a new PCC?

We also note in section 7.3 that the RPHA would also be multi-professional: we would want this to include user representation and user involvement.

Under section 7.5 entitled 'Health Improvement', we welcome the emphasis on a co-ordinated and consistent approach to tackling the key public health challenges, but we would seek further information on how this will work strategically. For example will it have a regional base with locally based satellites?

The LTCANI looks forward to establishing and in many cases building on the partnerships in order to achieve improvement in key public health measures. We also welcome the commitment to a more joined up approach within community planning.

We note section 7.17 concerning the role of the RPHA in re-designing services. LTCANI would stress that it is important that proper PPI practices are taken forward and that there is engagement with service users.

We welcome the reference in section 7.19 to the RPHA also being a source of public health expertise to other organisations including the voluntary organisations and look forward to working closely with the Agency once it is established. Additionally we believe that the relationship with the RPHA should be a two way relationship. Not only can the RPHA provide a service to the voluntary sector, but members of the LTCANI would provide information to the RPHA. The expertise of many of the LTCANI member organisations is crucial as we have been able to change lifestyles and attitudes with good self management programmes.

Comments on proposals concerning Agencies of the Department:

The LTCANI has no views to offer at this point on the proposed merger of the Mental Health Commission with the RQIA. The LTCANI has noted that the Bamford report recommended that it should remain a separate independent Commission.

Comments on the replacement of the Health & Social Services Councils:

The LTCANI would strongly support Option 1 as we believe there is a need for a strong regional entity to mirror the Department and the regional Board and to promote consistency of standards and service across the LCG's and the HSC Trusts. With the emphasis on service users the new PCC has to be strong. Additionally, Option 1 will provide five local PCCs under the umbrella of the province wide body, who will have the function of feeding into one

regional PCC. This will enable comparison in standards of care across Northern Ireland and has the potential to provide a good balance of evidence and experience across Northern Ireland.

The LTCANI would emphasize that there are normally only minimal variations regarding the prevalence of particular medical conditions from area to area, due to the size of the geographical areas in question. The possible variation will occur in accessing services, namely the provision and delivery of services in specific areas. Such variations in the provision or quality of service need to be monitored across the province.

In reference to function, the LTCANI stresses the specific importance of the first two functions -

- Represent the interests of the public;
- Promote the involvement of the public

As the main function of the PCC is to ensure effective public engagement there is a need for further clarification on the role and remit of the PCC. In previous legislation there was a duty on Trusts to properly engage with the PCC. It is essential that this provision is part of the new legislation.

The LTCANI views the PCC as having a key role in monitoring PPI and we look forward to working closely with the PCC in the future.

In terms of composition, we would like further clarification regarding the relationship of locally elected representatives within the PCC and within LCGs. While such involvement is valuable, it is possible that there could be a potential for a conflict of interest? If so, what checks and balances will be put in place within the system to ensure that this does not occur?

Additionally, we note in section 9.6 that the composition of 4 out of 10 local representatives would continue to be appointed. We would urge that this is changed and that the voluntary sector representation is increased to 4 out of

10 and the local representation reduced to 3 out of 10 as they have representation on LCGs.

In conclusion, the LTCANI looks forward to working closely with the proposed new structures and to sharing our experience and expertise with the view to bringing added value to the health and social service at all levels. Working together, we can help construct an appropriate person centred environment and encourage positive health outcomes.

Northern Ireland's health and social service has been through a long period of change and uncertainty. Over the coming months, we will be inputting into the legislative process and establishing and building up relationships with key stakeholders and the new institutions so as to help ensure that these measures bring about the maximum possible improvement in the health and social services available to our members and to all the people of Northern Ireland, and help secure the best possible health outcomes for us all.

For further information regarding the response please contact:

- **Steve McBride, LTCANI Chair – 2 Mount Eden Park, Belfast, BT9 6RA. Tel: 028 9066 6070; stevemcb@arthritiscare.org.uk**
- **Jayne Murray, LTCANI Vice-Chair – Diabetes UK Northern Ireland, Bridgewood House, Newforge Lane, Belfast. BT9 5NW. Tel: 028 9066 6646; Jayne.Murray@diabetes.org.uk**